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Letter to the Editor

Concerns of terminally ill cancer patients in their home environment

The concerns of Dutch terminally ill cancer patients who stayed in their home environment were explored, and in this 'Letter to the editor', we communicate some of our findings. In order to relate the actual *physical state* of the patients to their *concerns*, we constructed a relatively short self-report questionnaire of 19 items (partly open questions, partly using a Visual-analogue scale 0–10), including the WHO-functional scale. A total of 280 general practices in the northern part of the country were enlisted to approach patients with a life-expectancy of less than six months. The average general practice in the Netherlands takes care of about three to four terminally ill patients per year.¹ Therefore, during the recruitment period of seven months, about 500 patients were expected to meet our inclusion criteria. In principle, every Dutch inhabitant has access to basic homecare. In actuality, a total of 51 patients were included (by 34 GPs); 34 questionnaires were used for analysis (respondents: 14 male (mean age: 63.9, SD: 9.2); 20 female (mean age: 67.5, SD: 10.5); median time since diagnosis: 14 months; 28 patients (82%) lived with a partner). Six patients died before completion of the questionnaire, 11 questionnaires were incomplete.

Concerning the functional state, about half of the 34 patients was partially/totally confined to bed and partially/totally disabled. A majority, 26 patients (76%) suffered from two or more physical problems. Pain was most frequently mentioned ($n=23$, 61%), followed by fatigue ($n=13$, 39%). A majority of the patients reported *concerns* about the further *physical* course of the disease ($n=22$, 60%), as well as *non-physical* concerns ($n=23$, 68%, eg, concerns about partner, children, losing control, loss of independence, not being able to say good-bye). Patients with a WHO-functional state of 3–4 reported significantly more concerns (physical as well as non-physical) than patients with a score of 0–2 ($P=0.04$). Almost half of the patients ($n=16$, 47%) reported a threat to their dignity. Important aspects concerning 'maintenance of dignity' were: being able to say goodbye; dying at home; dying without symptoms; dying in peace; being clear of mind; being able to control the end (by euthanasia). Interestingly, ten patients (29%) stated they had *no* concerns at all (physical or non-physical). Furthermore, the majority ($n=28$, 82%) reported *not* being afraid of dying.

Of course, the results of our study permit only limited conclusions. Although many patients were approached, only 10% of the potential population ($n=51$) was included. This confirms the structural difficulty of including terminal patients in a study.² However, this study evokes several considerations.

A high level of physical complaints in the terminally ill, as reported here and by others,^{3–5} may indicate that, for many patients, symptoms are not under *optimal* (medical) control. Another notable point from our study is that not dying as such, but the *uncertainty* about the dying process was related to the severity of actual physical symptoms. This was also mentioned in other recent studies.^{6,7} (Although Heaven and Maguire,⁸ reported that loss of *independence* seems to be the major concern in terminally ill, we think this may be due to the fact that their study was performed in a *hospice* population, where symptom control may be more optimal than in home situations, and the threat of losing control and independence may be greater. A wish for euthanasia (mentioned a few times by patients), or the wish to die at home, can be viewed as an attempt to maintain personal control. Of course, cultural aspects may influence patients' perceptions on suffering, dying, death and euthanasia.)

In conclusion, we believe our exploratory study stresses the high value of symptom control. A lack of (feelings of) symptom-control may *evoke* concerns regarding the course of the disease, as well as concerning the process of dying. Adequate symptom management may not only alleviate current suffering, but also *prevent* physical and non-physical concerns in the future.

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